National Haemophilia

Haemophilia Foundation Australia

www.haemophilia.org.au

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2017 CONFERENCE

The 18th Australian & New Zealand Conference on Haemophilia & Rare Bleeding Disorders will be held at the Pullman Albert Park, Melbourne 12-14 October 2017.

Our Conference will bring together people with bleeding disorders and their families and carers, as well as health professionals, policy makers and industry. It is a great opportunity to learn more about care and treatment in Australia and New Zealand, and around the world.

Costs and registration information will be available in March 2017. To be kept up to date email your details to ncoco@haemophilia.org.au.

18TH AUSTRALIAN & NEW ZEALAND CONFERENCE ON HAEMOPHILIA & RARE BLEEDING DISORDERS

Melbourne • 12-14 October **2017**

Gavin Finkelstein is President, Haemophilia Foundation Australia

FROM THE PRESIDENT

Gavin Finkelstein

We are nearing the end of 2016, and our reporting to member Foundations at the Annual General Meeting in late October included a review of our work over the past year. Our published annual report will be available on the HFA website soon. I am pleased that the work on our new education resource for parents of a child newly diagnosed with haemophilia is now well underway and is to be published in the first part of 2017. Our Female Factors project is also progressing well with ongoing work being undertaken to develop resources for women and girls.

TREATMENT AND CARE

I recently met with the new CEO General Manager of the National Blood Authority (NBA), Mr John Cahill, and was able to reiterate comments to him in my earlier welcome letter to him. I confirmed that the community is keen to see a pathway developed for access to the extended half life clotting factors already registered for use in Australia, and for other emerging therapies when they are registered. HFA has many examples of the benefits of some of these treatments for the individuals who have participated in clinical trials. Reduced or no bleeding, longer periods between infusions, tailoring dose to suit the bleeding patterns of individuals, better adherence to prophylaxis, as well as a range of other factors leading to improved health and quality of life, strongly support access.

I also acknowledged to Mr Cahill that we are grateful for governments' commitment to treatment and care. I noted the support from the NBA for the Australian Bleeding Disorders Registry (ABDR) and MyABDR, and our work with Australian Haemophilia Centre Director's Organisation (AHCDO) and Haemophilia Treatment Centre health professionals, which enables patients to record their bleeds and work with their clinicians towards the best treatment plan for them on an individual basis. I assured him that we are very conscious of the high cost of all our treatment products and of our commitment to contribute to ways of evaluating outcomes for individuals and measuring the benefit to them so that governments have the evidence they need to justify the expenditure.

RESEARCH

It is important for us to contribute to the knowledge base that is developing about the treatment of bleeding disorders. There are important opportunities for us to add our voice to some of the research that is going on locally and internationally and I remind you that we upload research projects on our website that provide a chance for us as health consumers to participate in research – you may wish to participate.

HEPATITIS C

On another note, I implore people who have not yet had hepatitis C treatment to make an appointment with their health professionals for assessment. I have been fortunate to have cleared the virus following recent treatment with one of the new products and we are hearing many reports of others with bleeding disorders clearing the virus. You will see elsewhere in *National Haemophilia* that HFA is taking steps to ensure everyone has relevant information so they can take up treatment if they need it.

RED CAKE DAY DURING HAEMOPHILIA AWARENESS WEEK

Haemophilia Awareness Week and Red Cake Day were held this year from 9 to 15 October 2016. Haemophilia Foundation Australia and Haemophilia Foundations around the country worked together to raise awareness about inherited bleeding disorders.

There was great interest in the week and we had many supporters to help us fundraise and raise awareness over the week. The Bendigo Bank branches across Australia joined in partnership to raise awareness and funds, and schools, hospitals, libraries, families and local communities around the country received promotional materials to help them run their own Red Cake Days and Haemophilia Awareness Week activities. They held different types of events, but they all worked together with us to raise awareness about bleeding disorders or host a Red Cake Day. We are grateful for the support and uptake of this exciting event which we hope is becoming a regular feature on everyone's calendar.

THANK YOU NEWSLETTER

A newsletter highlighting all the events held during Haemophilia Awareness Week will be distributed to participants soon and will be available on the HFA web site. If you wish to receive a copy please email Natashia at ncoco@haemophilia.org.au

Thank you to everyone who participated in Haemophilia Awareness Week and Red Cake Day activities!

RED CAKE DAY AROUND AUSTRALIA

During Haemophilia Awareness Week
RED CAKE DAY
Red Cakes can change lives! It's true.
9-15 October 2016

CONGRATULATIONS TO THE WINNERS:

COLOURING-IN COMPETITION 2016

4 and under – **Marlo, Northhead** NSW

5-8 years – **Utano, Clayton** VIC

9-11 years – **Will, Waverton** NSW

Suzanne O'Callaghan is HFA Policy Research and Education Manager

MYABDR – WHY RECORD?

Suzanne O'Callaghan

In my education work on MyABDR, the discussion about why you should bother recording with MyABDR comes up regularly, particularly with young people. With their busy lives, dealing with their regular prophylaxis treatment or treating a bleed can feel like enough of an intrusion into their life, let alone recording it as well. So why is there so much emphasis on the need to record?

BEST PRACTICE TREATMENT AND CARE

MyABDR was developed as a tool to support best practice clinical care and treatment of people with bleeding disorders. What does this mean?

MyABDR is a secure app and web site that allows people with bleeding disorders and parents/caregivers to record treatments and bleeds at home and manage their treatment product inventory. It links directly to the **Australian Bleeding Disorders Registry (ABDR)**, which is the system used nationally by Haemophilia Treatment Centres for the clinical care of their patients. However, protection of the individual's privacy is critical to the system and the only data about them, their bleeds and treatment made available outside of the person's Haemophilia Treatment Centre (HTC) are de-identified statistics.

There was enormous excitement when MyABDR was established and released in early 2014. MyABDR is a collaboration between HFA, the Australian Haemophilia Centre Director's Organisation (AHCDO) and the National Blood Authority (NBA) on behalf of Australian governments – all the key players in the treatment and care of someone with a bleeding disorder: the patient, the Haemophilia Treatment Centre, the NBA which is the government authority that purchases and supplies treatment product, and the governments that pay for it.

So how does recording with MyABDR actually help best practice treatment and care?

KEEPING TRACK OF TREATMENTS AND BLEEDS

One of MyABDR's most important roles is to document instantly your or your child's bleeds and treatments and to link that into the national ABDR system that is used by your HTC. How is your treatment plan going? Are you having bleeds? If so, how often,

where, how is this related to your treatment? Does your treatment plan need to be adjusted?

Whenever you or your HTC want to look over your treatment and bleed history, MyABDR has a suite of online reports and lists that both you and your HTC can consult, if you have been recording:

- Lists and graphs that show how often you have treated, what treatment product you have used, and when and where your bleeds have occurred
- Excel spreadsheets you can download if you want to add it to a personal history at home.

Neil, who has severe haemophilia, has found this to be very important to his care.

"I have found MyABDR valuable to keep track of my bleeding episodes, how often I have one, and exactly where they occur - to see any target sites, eg elbow, ankle, knee. Without MyABDR, if I don't remember to record it in a diary, I forget and it's gone.

"When I do have my regular reviews with the HTC, the haematologist and I are on the same page. He has my MyABDR data in front of him. Before MyABDR, getting my information on the number of bleeds I've had and the amount of product to treat a bleed was very rare."

Neil has made recording a habit.

"It's one of those things I do straight after I've had the treatment, and also when I receive my new stocks of factor VIII, I record my stocks and then put the vials in the fridge. That's how easy it is. The product doesn't have to sit out of the fridge for a long time while I work out how to record it, because the system is so easy and quick to use."

TREATMENT PRODUCT USE

Having your treatment product inventory in MyABDR means that you can have your stock records at your fingertips – on your smartphone and your home computer. If your HTC or the product supplier contact you to see whether you need more stock, you don't have to look in the fridge to see how much you have left.

On the broader level, treatment stock usage patterns are immensely important. Overall statistics about the amount and types of product being used can help the government to stocktake and plan for purchase of future supplies. Anyone who recalls the treatment product shortages that were common thirty years ago knows how crucial this is. Treatment product is a precious commodity: it is lifesaving and can prevent bleeding complications like arthritis in joints; and it is also very expensive. Careful planning and purchasing agreements are essential for our national government, especially when they are accountable to all Australians for their actions.

FUTURE TREATMENTS

The 2016 World Congress highlighted many of the new innovations in treatment – for example, longer acting factors treatments that mean treatments do not have to be infused as often; and another treatment for haemophilia A that can be injected under the skin rather than into veins and has a novel approach to creating clotting.

To have access to these kinds of treatments in Australia, we will need to make a case for them, based on evidence. How do we compare them with treatments currently used in Australia? MyABDR is an obvious tool for creating real world data on this. The treatments and bleeds that each individual records can become part of the national de-identified statistics to show how a particular treatment works, including in individualised treatment regimens, and their impact on bleeding patterns. This is not only an effective way to understand and improve current treatments; it is a very valuable resource for our advocacy for future treatments.

For Neil, this aspect of MyABDR is another driving force for recording:

"MyABDR provides the Treatment Centre and relevant government agencies with the type of data required to provide people with bleeding disorders improved treatment and care. With these statistics in front of them they are more informed about the importance of these products to people with haemophilia and other bleeding disorders.

"It is at the 'end of the chain' that, in my opinion, the real value of MyABDR exists for people with bleeding disorders and for this reason the more it is used the better. MyABDR provides us with the opportunity to influence our level of treatment and the availability of improved factor."

AHCDO can use aggregated ABDR statistics to help answer questions about treatment and treatment outcomes. HFA has been eager to see what these reports can tell us and their potential to improve patient care.

However, bleeding disorders are rare and comprehensive data is needed from as many patients as possible to make meaningful results. While there are close to 700 registered MyABDR users, we are aware that quite a few registered users do not record regularly. We are looking into why this is an issue and ways to increase recording and ease of use. If you have any thoughts or experiences relating to this, please feel free to contact HFA and tell us about it! You can email or phone us, or use the online MyABDR feedback form - tinyurl.com/myabdr-feedback .

HFA's mission is to aspire to world's best practice in relation to treatment and care. This is reliant on the kind of evidence-based data that could be built through MyABDR and we will continue to work with the community, AHCDO and the NBA to achieve this.

Alex Connolly is the Clinical Nurse – Haemophilia at the Queensland Haemophilia Centre, Royal Brisbane and Women's Hospital

BLEEDING DISORDERS AND SURGERY - WHAT TO EXPECT

Alex Connolly

Having surgery can be a daunting prospect at the best of times and people with a bleeding disorder might be more worried than others. However, just because you have a bleeding disorder that doesn't mean you can't undergo surgery. It does require a bit more planning and keeping your health care professionals in the loop on what is happening. Patients should be managed ideally at or in consultation with a comprehensive Haemophilia Treatment Centre. In an emergency situation this might not be possible but consultation with the staff at the Haemophilia Treatment Centre is a must.

Any person undergoing surgery will have a pre-operative health assessment and again people with a bleeding disorder are no different. They do, however, require a consultation with a haematologist to develop a surgical plan and to determine the need for replacement therapy and what type.

At the pre-operative assessment the doctor will determine if you need a blood test. An inhibitor screening test and or a factor level may be required to adequately determine a treatment plan. When you are having surgery, in most cases a bolus dose of factor replacement is given about 60-90 minutes before your procedure. For people responsive to desmopressin (DDAVP) either an intravenous or subcutaneous dose is given. The bolus dose is to ensure a factor level peak while in surgery. This will limit bleeding during or immediately post-surgery. Patients with severe to moderate haemophilia may need a continuous infusion of factor replacement during and after surgery to keep their levels at optimum levels to decrease the risk of bleeding.

WHAT IS MINOR SURGERY AND WHAT IS MAJOR SURGERY?

Minor surgery is the type of surgery that can be often done as a day procedure and has minimal blood loss - procedures such as minor dental procedures, endoscopy/ colonoscopy, removal of skin lesions and arthroscopy

Major surgery is surgery that has a significant risk of large volume blood loss or blood loss into a confined anatomical space. Procedures such as joint replacements, spinal, cardio vascular, abdominal and intracranial (brain) surgery are considered major procedures.

Both minor and major surgery requires factor replacement therapy.

In the case of minor surgery this may be one to five days of therapy and in major surgery can be at least five to fourteen days. Both depend on the type of surgery and the severity of the bleeding disorder.

When undergoing a dental procedure it is recommended that patients take some form of antifibrinolytic agents such as tranexamic acid as this will promote clot stability and ideally should be administered shortly before induction of anaesthesia. Alternatively, oral administration (1 g 3–4 times per day) may be commenced a day or two before surgery to ensure adequate blood levels are present at the time of operation.

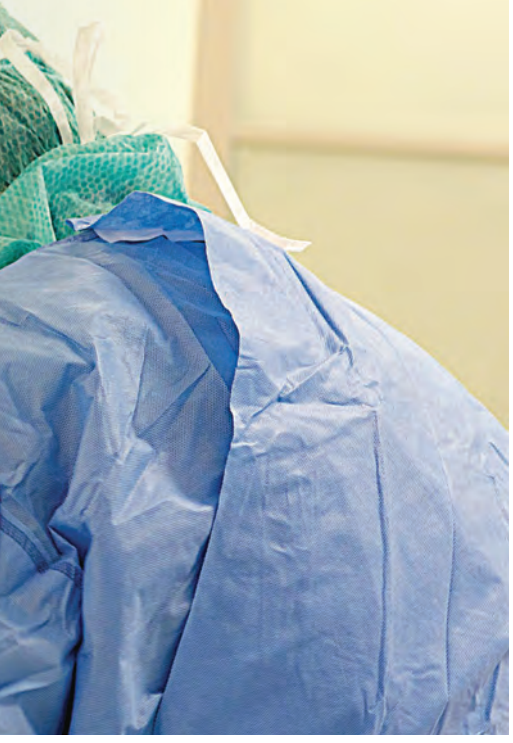
POST-OPERATIVE MANAGEMENT

Depending on individual needs and type of surgery, a hospital stay may be necessary. This can be an overnight stay or several days or weeks. At times patients may be able to attend an outpatient or GP setting to receive factor replacement for a number of days post-surgery. Factor levels may be checked regularly to determine the adequacy of factor replacement. If you have mild haemophilia A, and have had intensive replacement therapy for the first time, an inhibitor test should be performed approximately four to twelve weeks after surgery.

Your surgeon might want to see you for a follow up appointment and it is important that you keep this appointment even if you feel okay. The haemophilia team might be able to see you then as well to see how you are progressing and if you need anything from the team, please ask!

THINGS TO KEEP IN MIND

- Inform your Haemophilia Treatment Centre (HTC) sooner rather than later when surgery



is planned. It takes time to get factor organised particularly if the surgery is not at an HTC.

- Have your blood tests as required and let the HTC team know so results can be checked in a timely manner.
- Tell your specialist that you have a bleeding disorder. This may sound silly but you are the best advocate for yourself!
- The key to successful surgical management of the patient with a bleeding disorder is a multidisciplinary approach involving not only surgeons, anaesthetists and haematologists, but also laboratory scientists, specialist physiotherapists and haemophilia nurses. With careful planning, most surgical and invasive procedures can be carried out safely in persons with haemophilia and other bleeding disorders.
- A question not asked is a door not opened.

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GO FOR IT GRANTS

Have you ever wanted to be daring and take on a challenge? Or do something that's a bit scary? Or try something new?

Everyone experiences obstacles at some time, but you'll never know what you can overcome and achieve unless you ……GO FOR IT!

The Haemophilia Foundation Australia's Go for it Grants program assists people living with bleeding disorders take the first step towards achieving their goals.

WHO CAN APPLY?

The grants are open to anyone who has, or is affected by, a bleeding disorder.

There are 2 x $5,000 Go for it Grants on offer to provide winners with the financial support to help pursue their dreams.

What do you want to try? From study to advance your career, increasing your confidence and leadership skills with a public speaking course, or training to be the next sports star - the Go for it Grants can take you one step closer to realising your dream.

HOW TO APPLY

For a copy of the guidelines and application form:

- Visit the HFA web site - www.haemophilia.org.au
- Or contact HFA on 1800 807 173, email hfaust@haemophilia.org.au .

Applications close 17 February 2016.

Don't wait – just Go for it!

The Go For It Grants are supported by Pfizer.

Suzanne O'Callaghan is HFA Policy Research and Education Manager

MEN AND EARLY AGEING

Suzanne O'Callaghan

A fairly common comment over the last few years has been that with prophylaxis and home therapy, people with bleeding disorders no longer need to spend so much time in hospital – but that, ironically, this means there are fewer opportunities for them to connect for peer education and support.

This makes local Foundation activities like community camps and retreats and the men and women's breakfasts and other peer support groups an immensely precious time together and HFA works hard to find funding to support them.

The needs of men around early ageing is a new and challenging area for HFA. Our intensive work on The Female Factors, the women and girls project, has given a real insight into the education and peer support needs of women and girls in our community and the education resources and activities evolving out of this are very exciting. However, HFA's long experience of working with men in the community has shown that a different approach is required for men, and we also know that there is much more work that needs to be done to understand and respond to the issues around early ageing.

GROWING OLDER WITH HAEMOPHILIA

Advances in haemophilia treatment and care over the last few decades have meant that there has been overall increase in life expectancy for people with haemophilia, and many are now living into their senior years.[1]

Jason, now 44 years old, has mild haemophilia and recalls the very different story he was told when he was first diagnosed as a teenager:

"The doctor said my life expectancy was 30. So when you've got a kid who's 13 and is told they might only live to 30, how daunting is that!"

Growing older with haemophilia has raised another set of issues. Men with haemophilia who are now in their mid-20s or older lived through a time when prophylaxis was not yet available and there were treatment shortages at times. Most now have haemophilia-related arthritis from repeated bleeding into joints. They also experienced the hepatitis C and HIV epidemics in the bleeding disorders community in the 1980s, where many acquired bloodborne viruses from infected clotting factor concentrates.

As a result, issues of ageing, such as mobility and pain problems relating to arthritis, occur at a much earlier age in this generation of men with haemophilia – in general at around 35-40 years, although it can be at a younger age if they have had many bleeding episodes, particularly if they have had inhibitors and their treatment has not been effective.[1,2,3]

Even with mild haemophilia, and not having as many bleeding episodes as someone with moderate or severe haemophilia, Jason hasn't escaped without some complications.

"Now at the age of 44, I have some osteoarthritis in my right knee. My condition has absolutely had an effect on my life, and I do have to take care of myself more than others. I still keep active, training with the local over 35s football team, riding my bike and running on nice soft grass to keep my joints in order."

He also acquired hepatitis C, he suspects from a blood product he received when he was 13.

"I was diagnosed with hepatitis C in 2005 after a routine medical check. In the 1980s, most people with bleeding disorders were exposed to hepatitis C virus before it had been 'discovered'. I underwent treatment and I am now hepatitis C free."

RESILIENCE AND FATIGUE

HFA's community consultations have highlighted that the Australian bleeding disorders community has a culture of stoicism and resilience. As one man with haemophilia said,

"you learn to live with haemophilia. You're born with it, you grow up with it."

In spite of the good news that lifespans for many have increased, it is a community that remains aware of its vulnerability; that, for example, a head injury or a bloodborne virus like HIV or hepatitis C might tragically cut short a life.

"I think these haemophiliacs, they're like sports cars. They need to come into the pitt lane."

Far left: Jason
Left: Jason recovering from a bleed

The pain of bleeds and arthritis, the complications of bloodborne viruses if they have them, and limitations of their haemophilia can be challenging and make it hard to maintain a positive approach to their life.[4,5]

Jason comments,

"I still train with the over 35s masters football, but it's really frustrating. I train really well on the track, and people ask why I don't play, but I know my limitations. I still have to be careful what I do, and the difficult thing is the pain. People don't understand that if I get a bleed it will knock me around for a week or two."

MANAGING MULTIPLE HEALTH CONDITIONS

Apart from the mental fatigue of constantly fighting their physical problems, these men can become overwhelmed by the number of health conditions they have and the appointments and procedures required.

As one man with severe haemophilia in his 30s said to HFA,

"If you ask about the perfect consultation, I think these haemophiliacs, they're like sports cars. They need to come into the pitt lane. We get the arthritis, we get the hep C, we get the HIV, and those when they combine, create a mental health issue. And also there's counselling you need if you are in work. You are going to need some support to stay there. You need someone to help you get out of bed in the morning sometimes. You need rails in your bathroom. Other times you need other things."[5]

As they grow older, they face the same other health conditions associated with ageing in the general population: cancer, heart disease, kidney disease, mental health problems and lifestyle issues such as weight control and muscle development. These are usually managed by a general practitioner and will create another set of medical appointments for this generation of men. How can this be made more manageable for them?

PEER SUPPORT AND EDUCATION

HFA is starting new work to better understand the issues of early ageing in men with haemophilia and potential benefits of a "men's health" approach.

What opportunities are there to help men with haemophilia to support each other and maintain a resilient and positive approach to life?

And what kind of information and resources would be helpful for these men about their health and wellbeing – and how would it be best to deliver it?

The very successful men's peer support groups in some local Foundations show how valuable it can be to have a face-to-face relaxed environment for men to chat together about ordinary things like sport and cars, while at the same time sharing strategies for managing their health and learning about relevant health issues and services. But with mobility and distance issues, travel and meeting can be difficult. What other potential is there for connecting and peer support? Are there other ways that would suit this generation of men to come together? For example, online forums, phone or video or email networking, a virtual "men's shed"?

These are just some of the questions we are aiming to answer.

Hannah Opeskin, HFA Health Promotion Officer, will be leading the work on this project.

Contact Hannah for more information:
T: 03 9885 7800 (Mon-Wed)
E: hopeskin@haemophilia.org.au

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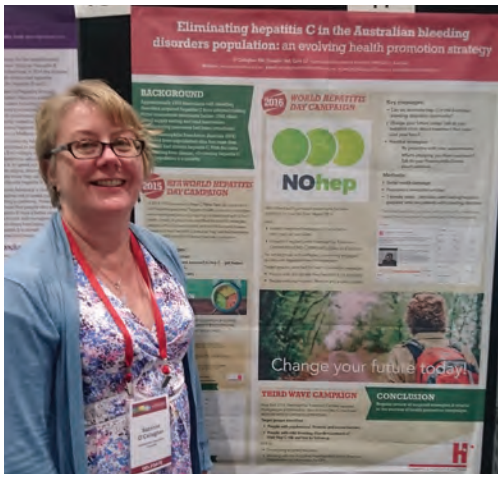
Suzanne O'Callaghan is HFA Policy Research and Education Manager

HEP C UPDATE



Suzanne O'Callaghan with the HFA hepatitis C poster

Suzanne O'Callaghan

HFA has been monitoring access to the new hepatitis C treatments for people with bleeding disorders around Australia. We have been pleased to see that most people have started treatment or have an appointment to discuss treatment. Some have now completed treatment and are going through the process of waiting the 12 weeks to hear whether the treatment has cured their hepatitis C.

WHAT'S STOPPING YOU FROM TREATMENT?

However, we are aware of some barriers stopping people from accessing the new treatments and are looking at ways to overcome this:

- Distance from testing and treatment centres
- Not convinced that the treatment will work for them or have few side-effects
- Financial problems
- Other priorities at this time.

If you or someone you know have a problem that is stopping you from accessing hepatitis C treatment, we strongly encourage you to talk to your Haemophilia Treatment Centre or your local Foundation or HFA to see what solutions can be found.

DO YOU KNOW YOUR HEP C STATUS?

Another concern for HFA is that some men and women with mild bleeding disorders may not know that they were at risk of hepatitis C if they ever had a clotting factor treatment before 1993.

Screening of the blood supply and HCV viral inactivation manufacturing processes for clotting factor concentrates were not introduced until the early 1990s, so anyone in Australia who had a clotting factor treatment for their bleeding disorder before 1993 needs to be tested for hepatitis C.

Over the last several years Haemophilia Treatment Centres have been checking the hepatitis C status of their patients in this group as they come in for a review. Men and women with mild disorders, including women who carry the gene and have only had an occasional need for factor treatment, may go for years without needing treatment and are often not in contact with their local Haemophilia Treatment Centre to have their hepatitis C status reviewed.

What is HFA doing about this?

- Social media campaigns to raise awareness in the bleeding disorders community
- Poster at the Australasian Viral Hepatitis Conference to raise awareness in the hepatitis workforce
- Working with the Australian Haemophilia Centre Directors' Organisation to alert general practitioners about this issue in case they have patients with mild bleeding disorders
- Working with Hepatitis Australia on a national campaign to reach the wider community of people with hepatitis C who have not yet accessed treatment.

CHANGE YOUR FUTURE

Having these new treatments available on the PBS is a great opportunity to have a future without hepatitis C for the bleeding disorders community. Some people have been worried that if they have treatment and it is not successful, they will not have other options. The aim of the hepatitis clinicians is to cure hepatitis C in all Australians – so please be reassured that if someone is unlucky enough not to be cured with the first round of treatment, other treatment options will be considered and there are more in the pipeline.

The Australian Government is committed to eliminating hepatitis C in Australia by 2026. Let's see if we can achieve this much earlier in the bleeding disorders community!

NOhep

"People with bleeding disorders and HIV remind us how vital it is to create a supportive and stigma-free environment for our community, and to acknowledge these individuals who inspire us by their positive attitude, resilience and determination to build a better future."

World AIDS Day is marked internationally on 1 December.

In 2016 the World AIDS Day national theme is **HIV is still here - and it's on the move**.

This is a time to raise awareness in the wider community about the issues surrounding HIV and AIDS. It is a day to demonstrate support for people living with HIV and to commemorate those who have died. Wearing a red ribbon is a way that you can show solidarity and raise awareness of HIV.

A TIME TO REMEMBER

This is also a time when we remember the members of the bleeding disorder community who were affected by HIV when in the mid-1980s HIV was transmitted through some batches of clotting factor treatment product.

Australians who attended the World Congress in Florida this year were deeply touched by the story they heard there of Ryan White, a young man with haemophilia in the USA, who acquired HIV from his clotting factor products in the 1980s and died when he was 18 years old. Even though he was still in his teens, Ryan became a community leader and spoke out against discrimination, having experienced it himself when he was banned from attending school. The impact of Ryan's work continues to live on. The US national Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was named in honour of Ryan and funds programs to improve availability of care for low-income, uninsured and under-insured people with HIV and their families.

As Sam comments in *Youth News*, the Ryan White story reminds us how important it is to remember of the legacy of HIV in the Australian bleeding disorders community. This tragic episode affected many people in our community, especially the people who lost partners, family members, children, patients, colleagues and friends. It cannot be forgotten.

However, as with Ryan's story, it is important also to remember the achievements of Australians in the bleeding disorders community affected by HIV – for example, the Mark Fitzpatrick Trust, named for a young Tasmanian boy with haemophilia who died of AIDS when he was 10 years old and recognising his mother Jenny's work in HIV education. The Trust was set up by the Australian Government to provide special financial assistance to people with medically acquired HIV and their dependents.

In 2016 HIV continues to be a part of our community's experience. Some people with bleeding disorders live on with the challenges of HIV. They remind us how vital it is to create a supportive and stigma-free environment for our community, and to acknowledge these individuals who inspire us by their positive attitude, resilience and determination to build a better future.

WHAT CAN YOU DO?

- Learn more about HIV in your community and share this knowledge with others
- Take action to prevent transmission of HIV by promoting safe sex practices
- Support and understand people in your community living with or affected by HIV
- And uphold the right of people living with HIV to participate in the community free from stigma and discrimination.

South Australians Save the date!

Information Session and Social Evening
Monday 16 January 2017

The Womens' & Childrens Hospital and Royal Adelaide Hospital are planning a late afternoon information session at the W&CH for people with bleeding disorders and family members – topics will include genetics, new treatments and care

Following the information session, we are planning a chance for people to meet and socialise. We will provide an early dinner snack for people who would like a picnic in the park, while others can go to the Big Bash cricket match at the Adelaide Oval later in the evening. We have pre-purchased some tickets and these will be available on a first come first served basis.

More details will be mailed to you, but please call HFA on 1800 807 173 (toll free) if you are interested in putting your name down for tickets.

TEAM.FACTOR

For the fifth year a group of cyclists led by Dr Simon McRae and Andrew Atkins, who both work at the Haemophilia Treatment Centre at the Royal Adelaide Hospital, will ride as **Team.Factor** to take on the BUPA Challenge Tour in South Australia on Friday 20 January 2017. The 2017 Bupa Challenge Tour will be from Norwood to Campbelltown, in total 157.50kms.

They will be fundraising for their favourite cause – Haemophilia Foundation Australia.

THE RIDE

The BUPA Challenge Ride is part of the Santos Tour Down Under in Adelaide, the first stop on the world elite cycling calendar. It gives regular cyclists the opportunity to ride the same Stage 4 route on the same day as the elite cyclists in the Tour Down Under.

THE TEAM

Team.Factor is a group of 15 men and women and includes:

Andrew Atkins, Mariette Boshoff, Marthinus Boshoff, Brad Clausen, Jaymie Clausen, Dan Drake, Uwe Hahn, Leon Langenhoven, Simon McRae, Cam McRae, Alexander Nicholson, Tina Noutsos, Thomas Viljoen, Kobie von Wielligh, Eric von Wielligh.

SUPPORT TEAM.FACTOR!

We are calling on all South Australians to come and cheer the team on at key spots in Birdwood, Mt Pleasant, Norwood and the finish line at Campbelltown.

Support Team.Factor at https://give.everydayhero.com/au/team-factor-bupa-challenge-tour-1 and we wish them all the best on the day.

Jane Portnoy is a Social Worker at the Ronald Sawers Haemophilia Centre at The Alfred, in Melbourne Australia.

TRANSITION – OH THE PLACES YOU WILL GO

Jane Portnoy

Visiting a major public hospital like the Alfred may not have been the first thing in your mind about things to do in your life, but if you are a young man or woman with a bleeding disorder it is likely that you will have to include an adult hospital like this in your list of places that you have to go.

GROWING UP AND TRANSITION

Growing up involves many steps. Some of these steps are clear and simple. Young people know that they will progress through school, graduate and move into trades, university or employment. They know that they will be able to make choices for themselves. Many are able to take on the responsibilities as required.

However, not everyone is ready at the same time, and there are lots of reasons why some people may not be so enthusiastic in their progression to a new stage. We know that having a chronic illness such as haemophilia certainly adds complexity and increases the risk of difficulties. Of course we also recognize that shifting medical care at this time can add to this burden. While there are many reasons that our systems are structured in this way, it also demands that we have to support this process with robust transition practices. These young people at this developmental stage and in this transition process are at a greater risk of neglecting their health care, and consequently having negative health outcomes. This is demonstrated in research and is seen in our everyday practice. These consequences can be far reaching.

LIFE CHANGES

Of course we all handle change in our own way. Some people see it as welcome and exciting. For others it's uncomfortable. Sometimes change comes with challenges that are predictable, other times they are unexpected.

Becoming an adult is an exciting time. There is more freedom and fun however there are also some new responsibilities.

There are new skills to learn and things to work through. These include dealing with driving, bills, finances, accommodation, work, university, voting, and also managing your health. This shift of responsibility from parents to a young person is part of their journey to independence.

Parents can find these changes really tough too. They have to make all these adjustments with their child, and they also have to start getting used to letting their child take on some of these responsibilities.

Changing your Haemophilia Treatment Centre brings its own concerns. There are new staff to rely on including doctors, nurses, social workers, psychologists, and physiotherapists. Young people may even have to go to a new hospital. On the positive side there are new opportunities for help.

So how can we try and make this an easier process? The Haemophilia Treatment Centre team think we are tuned-in to our patients' needs. But how can we really be? There are many variables - everyone has a unique personality and experiences and it takes us a while to get to know our new patients and their family or support crew. We will need patients and families to let us know what they need, and to give us a chance to get to know them. We do our best work when we understand who a person is, what is important to them and all about their medical issues.

DEALING WITH TRANSITION FROM A CHILDREN'S HOSPITAL

One of my jobs as a Social Worker in our team is to help our young patients to transition their health care to The Alfred. I regard this as one of the most important parts of my job. It can have a huge impact on the relationship that the young people and their family make with us.

At this stage of life the adolescent brain (15-25 year olds) is at its peak for learning, but still under construction for some of the other functions such as impulse control, and decision making. As part of taking on responsibility, people often make mistakes. It is often through making mistakes that learning and creativity is able to blossom. Hence it is a time for us to seize the opportunity, and support our young men and women, but also provide a safety net and supports to enable them to take on responsibility. It is also essential for growing up, that young people realise that they are accountable and that they do have to own their actions.

We encourage all people transiting to The Alfred to be involved with Haemophilia Foundations. There are a number of ways that this can happen, attending the camps or other events. These occasions have been carefully planned with the involvement of this centre and the Haemophilia Foundations. We see the benefits of attending these events over and over again.

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WHAT IS TRANSITION?

Here are a few definitions that I have found useful:

"Purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health care systems."[1]

"In the context of haemophilia, transition also refers to the continual process of learning about haemophilia and how to manage the many aspects of care. Transition is more complex for families living with haemophilia. Each stage of development involves extra learning for the parents and the child, and the comprehensive care team as well."[7]

"A multi-faceted, active process that attends to the medical, psychosocial, and educational/vocational needs of adolescents as they move from child to adult centred care."[6]

THE ALFRED 2016-2017 TRANSITION PROGRAM

In September 2016, we invited all the future patients of the Ronald Sawers Haemophilia Centre and their families to come along to a weekday evening to meet the team. There were about 14 patients invited.

Our goals were to

- Give these young men and women a chance to meet their future treating team
- Make The Alfred less unfamiliar/mysterious/alienating
- Give these new patients a chance to have a look around and to ask any questions
- Improve the transition experience from the Royal Children's Hospital to The Alfred because evidence based research tells us that transition is a time when health care engagement reduces anxiety about changing haemophilia and bleeding disorder treatment centre and hospital

THE PROGRAM ON THE NIGHT

We started with a tour of some parts of the hospital that patients are likely to visit when they come in with a bleed or for a clinic visit.

After this we introduced our team and there was an opportunity to ask questions. There were great questions: How appointments work? Why we have certain people in the team? A few attendees commented that they had learnt something new about their condition.

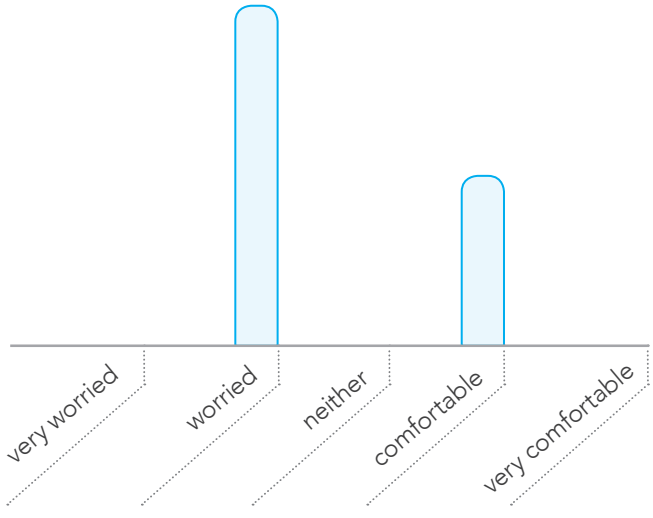
Haemophilia Foundation Victoria supplied supper, and after the formalities were finished we had pizza, sushi, drinks and an opportunity to talk together. In this more informal setup we provided the chance to open up discussion and an opportunity for patients and their families and the professionals to get to know each other.

The team at The Alfred really enjoyed meeting future patients and families and finding all about the interesting things that make them who they are including what their plans are for the future. We don't often get the opportunity to meet on an informal basis outside of the clinic.

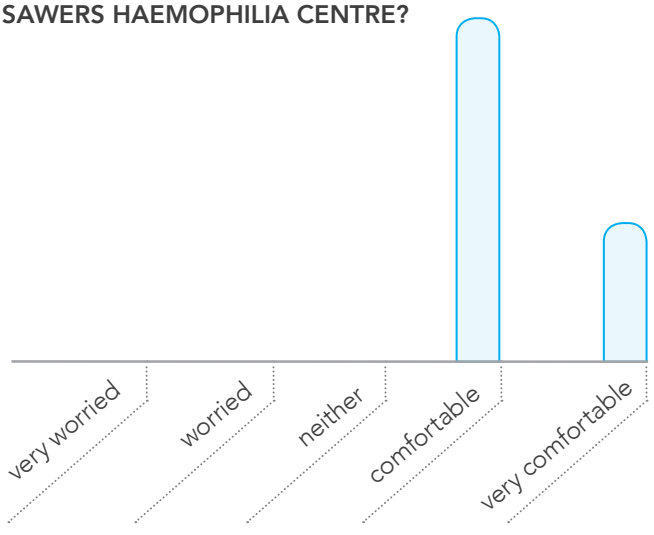
We felt that our pre-transition evening was successful and we asked participants for feedback at the end of the evening. Everyone who responded found the session reduced their anxiety about transition. We asked participants to complete a one page survey, to examine how we were meeting the goals that we had set. Our team feel it critical to future planning and in planning a broader transition program. Analysis of our service gives us information. Much research has been undertaken into the impact of poor transition. The consequences are significant and costly for consumers, their families, and for health service providers. The costs include, but are not limited to, quality of life, engagement, satisfaction, pain, and monetary costs.

SURVEY RESULTS

PRIOR TO THIS SESSION HOW DID YOU FEEL ABOUT CHANGING TO THE RONALD SAWERS HAEMOPHILIA CENTRE?



AFTER TONIGHT HOW DO YOU FEEL ABOUT CHANGING TO THE RONALD SAWERS HAEMOPHILIA CENTRE?



Many other patients were not able to join us, but we have been able to use this opportunity to contact them, and start the process of introducing our service and getting to know the patients.

The HTC teams from the Alfred and the Royal Children's hospital, and visiting doctors from Sri Lanka at the clinical meeting in October 2016

Photo: Jane Portnoy

THE NEXT STEP IN THIS TRANSITION PROCESS

The two teams from The Royal Children's Hospital and The Alfred had a formal clinical handover meeting. We used the ABDR to look at a summary of each person's medical information.

In December and February we will hold transition clinics to formally meet and review all our new patients. At these clinics we look forward to meeting our new patients. We are hoping to continue getting to know these young men and women and their families. In this way we are aiming to maximise their good health. We are also keen to reduce the negative impact of poor transition. We know that young people are generally motivated and it is important to harness this eagerness to improve their health. Usually engagement with a Haemophilia Treatment Centre is both an indication of and a pathway towards best possible health.

USEFUL ARTICLES

1.Blum RWM. Chronic illness and disability in adolescence. Journal of Adolescent Health 1992;13:364-368.

2. Bolton-Maggs PHB. Transition of care from paediatric to adult services in haematology Archives of Disease in Childhood 2007;92:797–801. doi: 10.1136/adc.2006.103804

3. Brand B, Dunn S, Kulkarni R. Challenges in the management of haemophilia on transition from adolescence to adulthood. European Journal of Haematology 2015;95 (Suppl 81):30-5. doi: 10.1111/ejh.12582.

4. Carrizosa J, An I, Appleton R, et al. Models for transition clinics. Epilepsia. 2014;55 (Suppl 3):46-51. doi: 10.1111/epi.12716.

5. Royal Children's Hospital Melbourne. Transition Support Service. Moving on to the Alfred: a tip sheet for young people with haemophilia. Melbourne: RCH, 2014. <http://www.rch.org.au/transition>

6. Spilsbury M, Chong D. Transitioning in Queensland: from teddy bears to apprenticeships! Presentation at the 16th Australian & New Zealand Haemophilia Conference, Sydney, 20-22 October 2011. <https://www.haemophilia.org.au/conferences>

7. 'Transitions towards independence'. In: Canadian Hemophilia Society. All about hemophilia: a guide for families. 2nd edn. Montreal: CHS, 2010 <http://www.hemophilia.ca>

8. Viner R. Barriers and good practice in transition from paediatric to adult care. Journal of the Royal Society of Medicine 2001;94(Suppl. 40):2–4

Hannah Opeskin is Health Promotion Officer, Haemophilia Foundation Australia

YOUTH UPDATE

Hannah Opeskin

FACTORED IN

Factored In continues to be a valued resource for the bleeding disorders youth community.

Factored In is regularly updates with the latest content including:

- A personal story about receiving a Go For It Grant to play golf in the United States of America
- A story about achieving success as a leader in the youth community
- A story about attending the WFH World Congress in Orlando

The articles and stories shared through the Factored In website are generated by our youth community and the Youth Lead Connect (YLC) participants as they tell their experiences being leaders and mentors in the bleeding disorders community. Many avenues in the community work to support Factored In; youth moderators continue to promote the website throughout their local community, and the Youth Working Group is involved in continual Factored In development by generating ideas for new content and contributing to content.

Sharing stories is a great way of keeping youth connected and is an integral part of Factored In. ***Become a member and share your story with the community***.

I encourage everyone to visit www.factoredin.org.au

YOUTH • LEAD • CONNECT

Youth Lead Connect (YLC) is a new leadership program developed by Haemophilia Foundation Australia (HFA) to build education and life skills for young people with bleeding disorders. The program began in 2015 and follows an application pathway similar to a job application process. The program encourages youth to step up in their local community and while increasing both their personal and leadership growth.

The program begins with an initial training weekend to develop leadership and mentoring skills as well as identify motivations of the youth to participate in the program.

An important part of the program is the 'Leadership Achievement Goals' component: after the training weekend youth develop 'Leadership Achievement Goals' in consultation with their local Haemophilia Foundation, and are required to work through these throughout the next 12 months before graduating from the program.

YOUTH LEAD CONNECT PROGRAM PROCESS:

- Youth apply to the program with a cover letter and referee
- HFA reviews applications and contacts all referees
- Letter of acceptance from HFA Executive Director
- Training weekend
- Development of 'Leadership Achievements Goals'
- Follow up & completion of Leadership Achievements
- Certificate of graduation

The 2016 Youth Lead Connect participants are engaged with their community and already demonstrated significant achievements throughout the past year:

- a YLC participant had a specific responsibility for planning and overseeing some of the children's activities at a family camp
- a YLC participant has done a talk to local youth with haemophilia about umpiring football
- a YLC participant has organised and planned a Women's Brunch that was held in in June
- two YLC participants have become committee members in their respective states after attending regular committee meetings

Details of two of these achievements are displayed in ***Youth News***.

APPLY NOW TO BE PART OF THE NEXT YLC PROGRAM

- Do you want to take the next step in your community and be more involved with other youth?
- Do you want to be a leader and gain some real life skills?
- Are you aged 16-30 years, have a bleeding disorder, carry the gene or have a sibling with a bleeding disorder?

Become involved in the Youth Lead Connect program!
Visit www.Factoredin.org.au to find out more.
Ask a question by contacting:
Hannah Opeskin
hopeskin@haemophilia.org.au
or via fax: 03 9885 1800

YOUTH NEWS

Caleb

On Sunday the 26th of June, six young people with haemophilia attended the Australia Football League (AFL) round 17 in Hobart, to watch the Hawthorn Hawks Play the Gold Coast Suns.

Before the game began, we met Chris Gordon, an AFL Boundary Umpire, who has umpired and also sat the Bench in AFL Grand Finals!

I'm a boundary umpire for the Tasmanian State League and it was handy to hear Chris talk about what he does. It was also interesting to hear how some things were different to what I do.

I believe this was beneficial for the youth attending and as well as their parents, as they were able to ask questions about the difference between what Chris and I do in our umpiring and also about how they could get involved in a similar way. Some of the topics that we covered included preparing for games and recovery. I have even used some of the tips that Chris gave us!

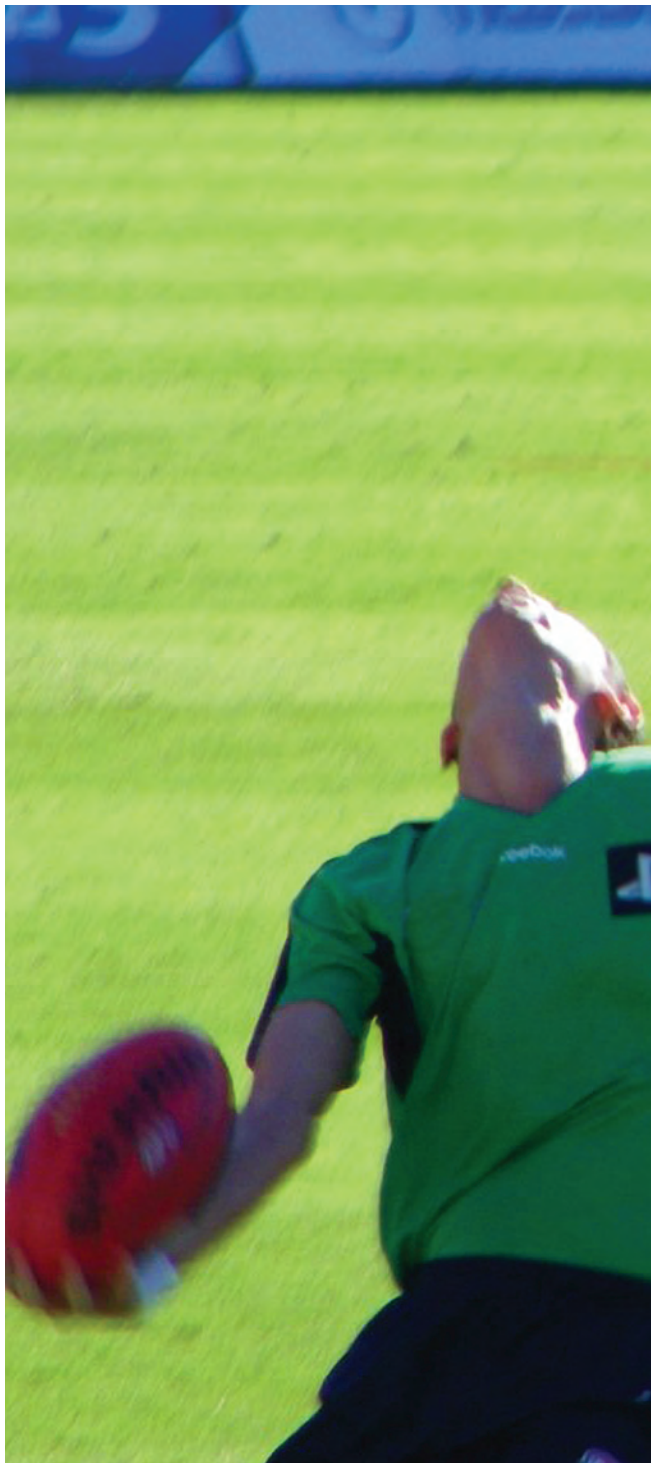
I helped create some pathways for the youth who were interested by providing them with key contacts that both Chris and I had found helpful in our umpiring careers.

A really special part of this event was being able to go into the Hawthorn rooms and watch how they warmed up – this was particularly exciting and interesting for me because I'm a Hawthorn supporter.

After we saw the team warm up, we went back to our seats and enjoyed the game!

Go Hawks!

Chris' story is on Factored In – visit www.factoredin.org.au to read more.



FIND OUT WHAT THE YOUTH ARE UP TO

Photo: WFH

Jenna

I was given the opportunity to attend and speak at this year's World Congress in Orlando. This was my second Congress, after attending ours in Melbourne in 2014. I would like to share with you a few parts of this year's Congress I enjoyed the most.

WFH YOUTH LEADERSHIP ADVISORY COMMITTEE MEETING (YLAC) & YOUTH SESSION

I was invited to speak at the youth session, held just before the Opening Ceremony. The session was about youth transitions and advocacy. I shared my story of transition from pre-diagnosis to diagnosis (as a young person diagnosed after childhood), and I very much enjoyed sharing my story. In this session, those in the room also heard stories from fellow youth leaders from countries such as Egypt, the United States and Mexico about how they manage their bleeding disorder personally, as well as the work they do as advocates in their countries. I learned a lot from fellow youth leaders and advocates in this session - if you are interested in being a leader and advocate in the community, I can definitely recommend being involved at the international level. There is a lot to learn from the rest of the world, and they're pretty cool people too.

FOCUS ON TREATMENT IN THE DEVELOPING WORLD

A theme that came through in many sessions this year at Congress (including the youth session) is the gap in availability in treatment and care in developing countries around the world. In our corner of the planet, that includes countries like India, Bangladesh and Indonesia. For most patients in these countries, access to factor concentrates, and even older products like cryoprecipitate and fresh frozen plasma, is not possible or is severely restricted by cost. These patients often get their first access to prophylaxis at events like World Congress through the on-site treatment room and product that has been donated, then have to return home with little or no product. Hearing from other young people in the session I spoke in very strongly highlighted to me how lucky I am to have been born in Australia with access to safe and free treatment. A WFH priority is to close the gap between those who have treatment and those who have none.

I can recommend a video series on Treatment for All produced by WFH and a fellow youth advocate, Patrick James Lynch - www.wfh.org/en/treatmentforall

FOCUS ON WOMEN WITH BLEEDING DISORDERS

Perhaps my favourite session at the WFH 2016 Orlando Congress (after the one I spoke in!) was entitled: ***Bleeding & Women - Time for a Paradigm Shift***. There is currently a strong understanding around the world that the area of women with bleeding disorders is under-researched and under-supported, but there is a lot of support for change. There was an exhibition booth at the Congress exclusively run by women, and a keen interest in perspectives from females with bleeding disorders - I personally had conversations with other youth with bleeding disorders, industry and NMOs that show that now is the time for change. I encourage females to get involved in the community and share your experiences - and as someone who has spoken at in a Congress session about my female-specific bleeding issues, I can also attest to the fact that you will be supported to be involved.

NEXT UP, GLASGOW!

The Scots introduced themselves in both the Exhibition Hall and at the final dinner - with scotch, kilts and bagpipes! A World Congress is a wonderful experience for a person with a bleeding disorder. Attending an overseas Congress takes quite a bit of planning but is something I recommend.

YOUTH NEWS

Sam

Sam is a leader and mentor of the youth community across Australia and is involved with his local community through Haemophilia Foundation New South Wales. Recently, Sam was the recipient of a Go For It Grant, which helped him to attended the WFH Congress in Orlando. Here is part of his exciting experience.

The Congress was an absolute whirlwind of making friends, shaking hands and learning about the current state of the bleeding disorders community.

The first and most humbling experience was meeting the sheer amount of people from around the whole world that are all here for the same reason - whether they are people with a bleeding disorder looking to see what advancements are happening and how other people are treating, to the doctors and nurses that are looking to other countries as to how they are treating people and the different procedures. That's thousands of people, all experiencing the same thoughts and problems that you are. Haemophilia can sometimes be a really personal disorder to suffer through sometimes, and knowing that there are so many other people just like you is eye-opening, and really helped to set me at ease in this large crowd of so many people.

HIV AND RYAN WHITE

I attended a talk hosted by Jeanne White-Ginder, the mother of Ryan White, a teenager with haemophilia who died at the age of 18 from HIV/AIDS after getting it from HIV-infected clotting factor. This talk was incredible. It was inspiring, touching and an amazing window into a part of haemophilia history that is often not talked about among people in my generation. I had absolutely no idea about the story of this young man and how tragic it was – and what he achieved. It must be hard for the older generations to talk about, considering all of the loss that they suffered at the hands of contaminated blood products. I think it's important to keep this dialogue going with the younger generations of people with haemophilia so that they can begin to understand just how good current treatments are and how lucky they are compared to just a decade or two ago.

WOMEN AND BLEEDING DISORDERS

The major session that I want to talk about was Bleeding and Women: Time for a Paradigm Shift. I have a lot of female friends in the bleeding disorders community, so this was one of the sessions I was determined to attend.

The five different speakers all covered a different area of the female bleeding disorders community. Many different perspectives and statistics were given out during the talk. They discussed the difference in haemophilia treatment and testing between females and males. One example of this is the age where they are often tested for their factor levels.

The second speaker, Tatiana Markovic from the Serbian Hemophilia Society talked about the percentages and amount of females with or carrying bleeding disorders that Serbia has, with that number being 850 female patients. 30% of those female patients are symptomatic carriers. Speaker number 3, Yannick Cole from the French Hemophilia Society talked about the experiences that females have had getting treated and getting to be classified as "having haemophilia" rather than "having haemophilia symptoms."

Hearing about the lack of information and awareness about women with bleeding disorders was shocking for me, and it is truly my belief that the haemophilia community can be very male-focused. It can be hard for females to be properly heard or talk about their problems on a larger stage. I hope this discussion at a world-wide level can achieve some changes now.

WFH GENERAL ASSEMBLY

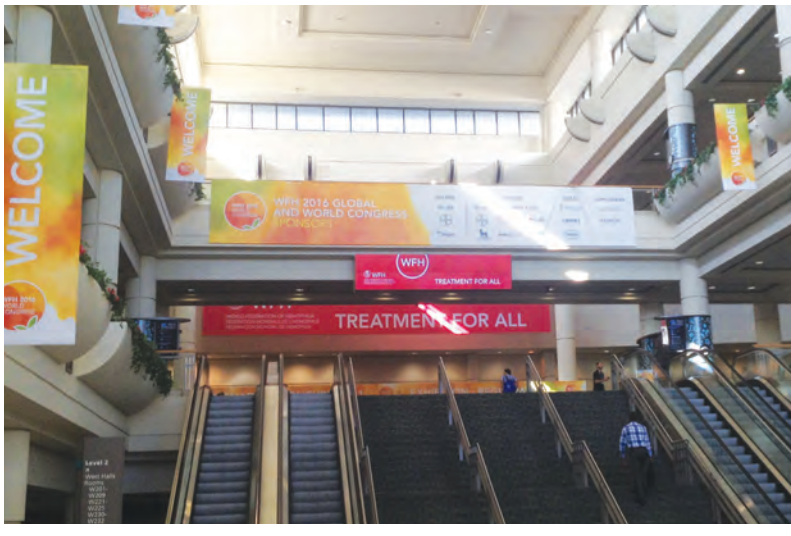
Haemophilia Foundation of Australia (HFA) also granted me the amazing chance to sit-in and be one of the official Australian representatives at the World Federation of Hemophilia General Assembly, the day after Congress finished. I got to sit behind Gavin Finkelstein, HFA President, and observe the proceedings of adding new countries to the membership of WFH. After the first session, Gavin even suggested I take over as the voting

FIND OUT WHAT THE YOUTH ARE UP TO

representative for the rest of the day! Once we came back from morning tea, it was my turn to sit, and be the official representative of Australia on the global haemophilia stage. The HFA decisions had already been made so my job was to represent them. I had the opportunity to cast the HFA vote for new members of the WFH board, as well as casting the HFA vote on the changing of by-laws and the location of one of the Congresses coming up in a few years! (Not spoiling it though!) Thank you HFA for trusting in me, and giving me the chance to represent the country on the world stage!

There was plenty of fun to be had outside of the Congress too! The multitudes of lunches, dinners and shopping with friends was just as important and as helpful as attending sessions to me! Overall, the WFH 2016 World Congress was a humbling and exciting experience and a wonderful event to be a part of. Understanding the sheer scale of the community and the different opportunities and friendships that it opened for me has changed my life for the better and inspired me to give back more to this community. I would urge everyone to attend one of these Congress's if you could. The amount you can learn, the people you get the chance to meet, and the lasting friendships you can create are reasons enough. Please keep checking National Haemophilia as well as Factored In for more updates and stories from my trip to Orlando, Florida.

Visit www.factoredin.org.au to read more about Sam's experience of going to the World Congress.



CALENDAR

World Haemophilia Day
17 April 2017
www.wfh.org/whd

Haemophilia Awareness Week
8-14 October 2017
Tel: 03 9885 7800
Fax: 03 9885 1800
Email: hfaust@haemophilia.org.au
www.haemophilia.org.au

18th Australian & New Zealand Conference on Haemophilia & Rare Bleeding Disorders
Pullman Albert Park, Melbourne
12-14 October 2017
Tel: 03 9885 7800
Fax: 03 9885 1800
Email: hfaust@haemophilia.org.au
www.haemophilia.org.au

Haemophilia Foundation Australia (HFA) values the individuals, philanthropic trusts and corporations which have made donations to support education activities and peer support programs and Corporate Partners that sponsor programs to enable HFA to:

- represent and understand the needs of the community
- provide education and peer support activities to increase independence and the quality of lives of people with bleeding disorders, and their families
- encourage clinical excellence in haemophilia care, and promote research.

Biogen

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Pfizer

Gavin Finkelstein, HFA President,
Sharon Caris, HFA Executive Director,
and the staff of Haemophilia Foundation Australia
wish you a safe and happy festive season.

Thank you for your support during the year
and we look forward to working with you again in 2017.

HAEMOPHILIA FOUNDATION AUSTRALIA

The HFA office will close at 12 noon on Friday 23 December 2016. We will reopen fully on Monday 9 January 2017. During that time if you have any queries or need to contact HFA, please note that messages left on the answering machine will be monitored. If you have an urgent matter please contact Sharon Caris on 0410 419 914.

Haemophilia Foundation Australia acknowledges the funding and assistance received from the Australian Government Department of Health which makes this publication possible.